



iCARDEA

“An Intelligent Platform for Personalized Remote Monitoring of the Cardiac Patients with Electronic Implant Devices”

SPECIFIC TARGETED RESEARCH PROJECT

PRIORITY Objective ICT-2009.5.1: Personal Health Systems - a) Minimally invasive systems and ICT-enabled artificial organs: a1) Cardiovascular diseases

iCARDEA D5.1.1 Personal Health Record System

Due Date: November 30, 2011
Actual Submission Date: December 02, 2011
Project Dates: Project Start Date : February 01, 2010
Project End Date : January 31, 2013
Project Duration : 36 months
Leading Contractor Organization: SRFG

Project co-funded by the European Commission within the Seventh Framework Programme (2007-2013)		
Dissemination Level		
PU	Public	x
PP	Restricted to other programme participants (including the Commission Services)	
RE	Restricted to a group specified by the consortium (including the Commission Services)	
CO	Confidential, only for members of the consortium (including the Commission Services)	

Document History:

Version	Date	Changes	From	Review
V0.1	November 08, 2011	Initial Document	SRFG	All partners
V0.2	November 29,2011	Updated technologies , tool sections and screenshots	SRFG	SRDC
V0.3	November 30, 2011	SRDC review	SRDC	SRFG
V0.4	November 30, 2011	Updated Document according to comments	SRFG	SRDC

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1 Introduction

1.1 Purpose

This document describes the software supporting the Patient Empowerment Framework developed in Task 5.1.

The Patient Empowerment Framework (PEF) is a term used to describe the software and tools that are used to create a deployable system called a PHR system (PHRS). The PHRS system might include or access components from other tasks from other Work Packages (WP), such as from WP5 and WP6 Task 6.3 PHR Interoperability. With this document, the term PHR Portal is also mentioned. The PHR portal is where a user interacts with the PHR system (PHRS). Task 5.1 handles the infrastructure for the PEF, the PHR Portal and the most of the PHR system, except for components derived from WP 6 Task 6.3, PHR Interoperability.

1.2 Definitions, acronyms and abbreviations

Abbreviation/Acronym	DEFINITION
CMS	Content management system. The use of the term is meant to include social and collaborative software e.g. Wikis, Blogs, Forums
JSF	Java Server Faces (User Interfaces)
HIS	Hospital information System
OpenID ¹	A framework and standard that describes how to authenticate users in a decentralized manner
PEF	Patient Empowerment Framework
PHR Portal	The PHR portal is where a user interacts with the PHR system (PHRS)
PHR or PHRS	Personal Health System based on the PEF for example.
UI	User Interface
WP	Work Package

Table 1 List of Abbreviations and Acronyms

¹ OpenID <http://openid.net/>.

2 Principals followed

The Patient Empowerment Framework (PEF) development history included prototypes that experimented with various technologies, such as web frameworks, user management/authorization software, persistence technologies and portal technologies. This experimentation helped to make final choices using the latest technologies and approaches; it is hoped that these choices support the reuse and further development of the PEF.

Keep it simple and smart

The PEF is based upon particular key technologies that are important for future uptake, reuse and development as an open source project.

Choose a web framework technology that does not hinder development and uptake

A suitable web framework should be based on specifications and standards, support event-based programming, and should be acceptable and perhaps popular to mainstream developers. There were prototype experiments with various popular web technologies that might ease future development, such as Grails², ZK³, Vaadin⁴ frameworks. However, the JSF 2.0 framework^{18 22} coupled with the PrimeFaces²³ UI component library were chosen. The Groovy⁵ programming language used in the Grails based prototype, became the primary programming language next to Java. More discussion is provided later in the technology sections.

Facilitate flexible data models/ modelling, and prepare for “Big Data”

The persistence technology needs to support flexible data models now and for future development. PHR systems and healthcare applications must confront the issues of Big Data⁶ and the plethora of data silos. A NoSQL⁷ document-oriented persistence solution addresses the main concerns of Big Data and data model flexibility. Furthermore, it is important to include a Map Reduce engine to also to optimize data model flexibility. Map reduce functions might aggregate and compile data into new views for reporting or sharing. The goal is not to have a defined and limited set of models; instead it is necessary to have the flexibility of create new views over heterogeneous models. For example, the success and popularity of CouchDB⁸, was convincing. Data flexibility and the handling of Big Data are important aspects of the PEF because new data models or views can be created new or including existing models. Furthermore, the PEF includes a common data model that can be reused, however, it includes properties needed by the common reusable UI controller software and UI functionalities. This approach is the one main difference with the current PHRS systems such as Microsoft HealthVault³¹. The PEF is expected to

² Grails web framework <http://grails.org/>

³ ZK <http://www.zkoss.org/>

⁴ Vaadin <https://vaadin.com>

⁵ Groovy <http://groovy.codehaus.org/>

⁶ Definition: Big Data http://en.wikipedia.org/wiki/Big_data

⁷ Definition: NoSQL <http://en.wikipedia.org/wiki/NoSQL>

⁸ CouchDB <http://couchdb.apache.org/>

be flexible in terms of data modelling for new and existing models or integrating new data services.

Facilitate Integration of health applications, social software or content management portals

Integrating social /collaborative software or content management can provide advanced functionalities to health applications and potentially reduce more data silos from home grown solutions. Popular portal software includes Atlassian Confluence and Liferay²¹ portal. One fundamental problem to integrate other applications in PEF was the handling of a user's digital identities whereby each application manages its own user accounts. Users usually login to each site with a local account, acquiring many user accounts. Single Sign-on⁹ solutions became popular as a means to provide a single access point. OpenID is another open standard and protocol that enables user authentication by a common provider over many applications that support OpenID. One way of integrating applications with PEF is through OpenID. The goal is to have a user with one digital identity recognized across multiple applications.

A user's digital identity should be decentralized and reusable across many web applications, particularly for applications residing on the same web domain. For this reason, the use of OpenID¹ is an attractive replacement of traditional user management and authorization strategies. The user should be able to use one identity to access various applications. The main issue for the PEF was to facilitate the integration of both external portal products and even healthcare applications. This is especially important for applications residing on the same web domain because it is possible for the user might seamlessly use several applications after logging in once. The primary challenge of OpenID is how an external application adapts OpenID approach in their user management solution. For example, Atlassian Confluence and other portals might require first that the user creates a portal user account and then later assign one or more OpenIDs to their account. Traditional user management coupled with OpenID is one scenario that still requires the user to create a local account. Other applications might use the OpenID approach solely without requiring the user to create a local account. The PEF provides some configurable approaches, however, it will be up to future implementers to customize the OpenID solution. In conclusion, the use of OpenID enables the PEF to better integrate with healthcare applications and content management/social software portals. When applications reside under one website domain, the approach, when possible, is to configure all applications to accept an OpenID without challenging the user to login multiple times. In this way the user experiences "one" health application

Support Interoperability and internationalization

Sharing information with clinical systems is based on interoperability services (Task 6.3, D6.3.1) that use the IHE CM Profile and utilize standardized vocabularies such as UMLS, LOINC, and SNOMED. The PHRS interoperability services are available for healthcare applications and include client software and a SKOs¹⁰ based RDFS¹¹ ontology (Simple

⁹ Definition: Single Sign-on http://en.wikipedia.org/wiki/Single_sign-on

¹⁰ SKOS Single Knowledge Organization <http://www.w3.org/2009/08/skos-reference/skos.html>

Knowledge Organization) containing relevant standard vocabularies, simple labels, and organized with relevant query tags for use by User Interfaces, for example. The PHR portal sends messages containing new or updated patient health information to the PHRS interoperability component and are persisted separately by that component.

Internationalization of the User interfaces and terminologies are also supported using Java internationalization support (I18)¹². Together with additional PEF software tools, the standard java approach also complements internationalization of the standardized vocabularies.

Collaborate over User Interfaces using Mockup tools

The mockup tool, Balsamiq Mockups¹³, was used to create mockup User Interfaces for collaborating with and receiving feedback from experts in the iCARDEA consortium. The following figures are examples of mockups of two User Interfaces. Figure 1 shows the mockup for the smoking risk factor and Figure 2 shows the mockup for about Physical Activities. The actual User Interfaces are shown in Figure 20 and Figure 24, respectively.

Figure 1 - Mockup Risk Factor Smoking

Figure 2 – Mockup Physical Activities

¹¹ RDFS <http://www.w3.org/TR/rdf-schema/>

¹² Internationalization I18 <http://java.sun.com/javase/technologies/core/basic/intl/>

¹³ Balsamiq Mockups <http://www.balsamiq.com/products/mockups>

3 PEF PHR Portal Functionalities

This chapter describes the main functionalities of the PHR web portal; the portal is split into three high level sections that are accessible in the portal's navigation menu:

- Patient Information – comprising the management of the patient's health data
- Information and People – offering information and health material for CIED patients, access to CIED communities and contact to care takers
- Privacy and Administration – offering services for organising the patient's privacy

3.1 Patient Information

Patient Information comprises an overview of the patient's health data from different perspectives:

- Health observations – includes periodically or occasionally recorded patient data such as blood pressure or current symptoms or problems.
- Action Plan - includes an Action Plan allowing the patient to organize such observations of daily living or other health-related event such as an appointment with his/her cardiologist.
- Profile – describes the patient's profile from different categories such as risk factors, sport activities and activities of daily living
- Monitoring – refers to an overview for vital signs (e.g. blood pressure, weight) as graphics.

The following sections presents examples of UIs for gathering patient information.

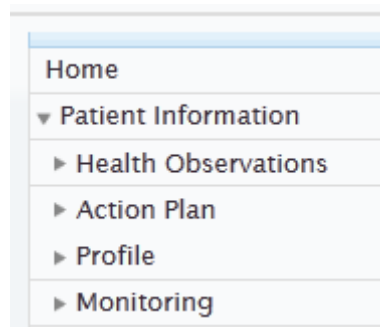


Figure 3 – Menu: Patient Information

3.1.1 Health Observations

The menu item “Health Observations” comprises patient data collected and recorded by the patients themselves. This includes in the current version of the PEF portal blood pressure, body weight, problems and medication compliance.

3.1.1.1 Recording Blood Pressure

Figure 4 shows the form for inserting blood pressure and heart rate on a daily basis. An overview form (see Figure 5) lists all recorded values. An historical overview of blood pressure and heart rate data can also be presented as a graphical view depicted in Figure 6.

Figure 4 – Dialog view: Blood Pressure

Blood Pressure				
+ create Chart				
Options	Date	Blood Pressure	Heart Rate	Comments
	2011-11-01	111/65 mmHg	123 bpm	drank water before
	2011-11-09	150/91 mmHg	99 bpm	nervous
	2011-11-17	132/86 mmHg	79 bpm	no worries

Figure 5 - List view: Blood Pressure

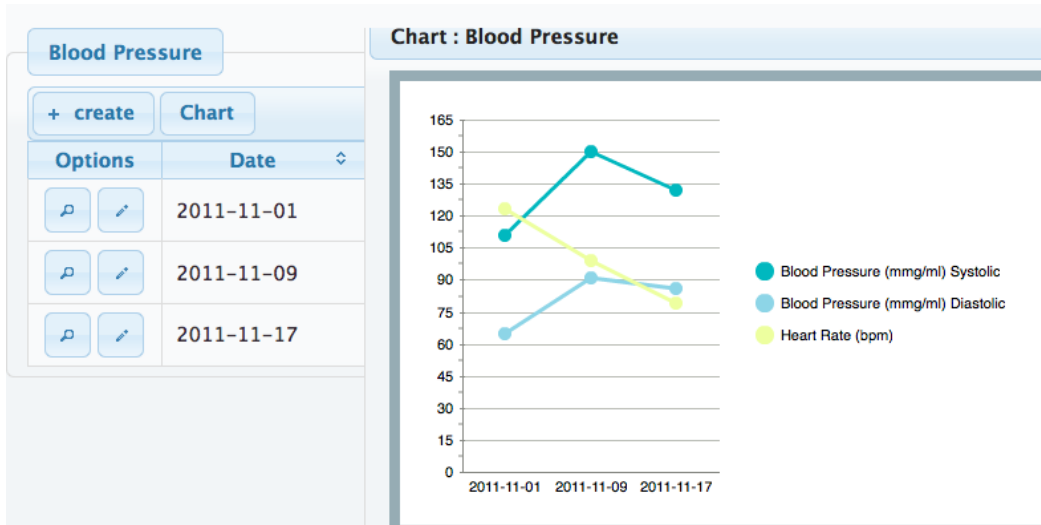


Figure 6 - Chart and List View: Blood Pressure

3.1.1.2 Recording Body Weight

Figure 7 shows the form for inserting body weight and height; the height is inserted from the known height and available here for modification. An overview form (see Figure 8) lists all recorded values and additionally calculates the **body mass index (BMI)** based on weight and height. An historical overview of body weight data can also be presented as a graphical view depicted in Figure 9.

Body Weight

Started: 2011-11-17

Weight: 82 kg

Height: 175 cm

Comments: exercise and less sweets

Save Cancel

Figure 7 – Dialog view: Body Weight

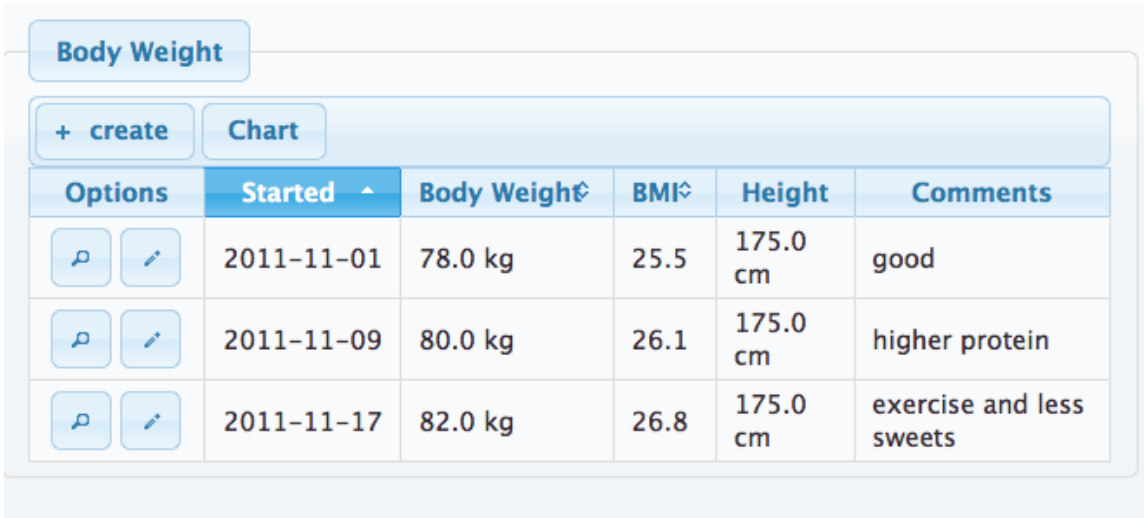


Figure 8 - List view: Body Weight

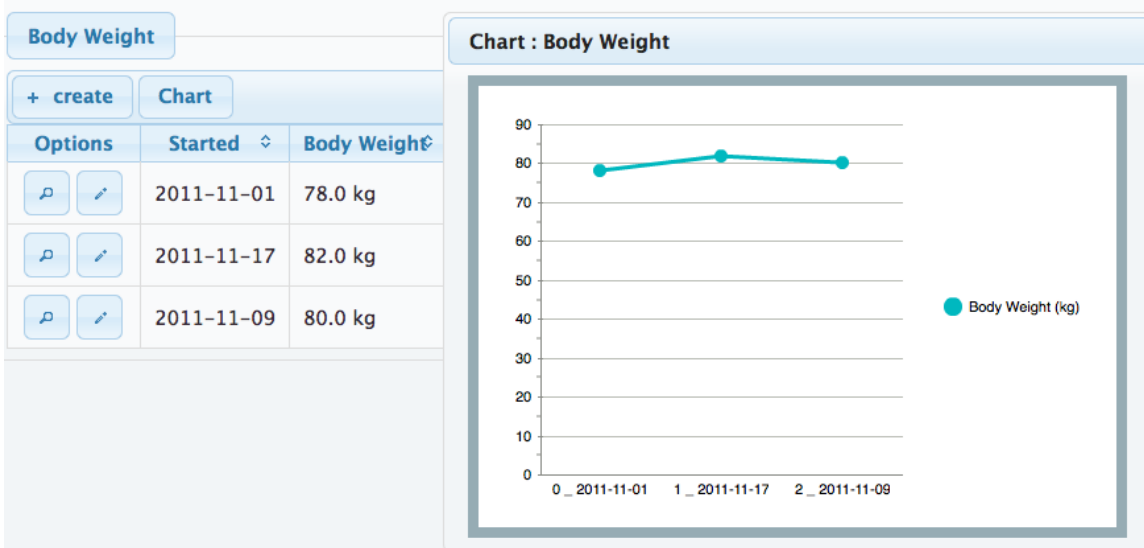


Figure 9 - Chart and List View: Body Weight

3.1.1.3 Reporting Health Problems (Symptoms)

The patients can provide a list of their health problems to share with their doctor either directly during consultation or by sharing via the interoperability services.

Figure 10 presents the dialog form for inserting an observed problem or symptom on a daily basis. The patient can indicate whether s/he has currently a problem or whether the problem disappeared. The list of problems comprises typical symptoms related to CIED

patients (see Figure 11). An overview of recorded problems and their status are presented in a chronological order in Figure 12.

Problem Description

What is the problem?

Are you still having this problem?
 This is a current problem since This is no longer a problem as of

Date (yyyy-mm-dd)

Comments

Figure 10 – Dialog view: Problems (Symptoms)

Problem Description

What is the problem?
Please Choose

- Please Choose
- Ankle swelling
- Bleeding gums
- Bruising symptom
- Chest pain
- Diarrhea
- Extra bruising or bleeding
- Extra pillow to sleep at night
- Fatigue
- Fatigue - symptom
- Fever
- Foot swelling
- Palpitations
- Rashes
- Shortness of breath
- Temporary loss of speech
- Temporary weakness
- Vomiting
- Weakness present
- Weight increased

Are you still having this problem?
Date (yyyy-mm-dd)
Comments

Figure 11 - Controlled vocabulary for UI and PHRS interoperability services

Problem Description				
+ create				
Options	What is the problem?	Status	Date	Comments
 	Bleeding gums	This is a current problem since	2011-11-02	after brushing teeth
 	Ankle swelling	This is no longer a problem as of	2011-11-09	

Figure 12 - List view: Health Problems (Symptoms)

3.1.1.4 Medication Compliance

The medications sections display three views: active and inactive medications and a history of updates to the medication items by the patient. The patient might manually enter their own medications, both prescription and over the counter. In iCARDEA medication data are also imported from the Hospital Information System (HIS). Figure 13 presents the dialog form for inserting a medication. The patient can indicate dosage, frequency and whether s/he is currently taking this medication or whether s/he stopped the intake. Figure 14 depicts an overview for medication compliance.

Medication Name	Simvastatin		
Are you taking this medication now?	Yes, I currently take this medication since		
Dosage	How many?	Units	
	<input type="text"/>	milligrams mg	
	How often? (example 2 per day)	When taken?	
	Every day	in the morning	
Who prescribed the medication?	<input type="text"/>		
Reason for taking this medication	Cholesterol		
Comments	<input type="text"/>		

Figure 13 – Dialog view: Medications

Medication					
Medications - no longer taking		Medications - history of updates			
Medication Name	Status	Date	Keyword	Dosage	Prescribed by
Simvastatin	Yes, I currently take this medication since	2011-11-23	Cholesterol	20.0 milligrams mg Every day in the morning	
Nomexor	Yes, I currently take this medication since	2011-11-15	Hypertension	1.0 pills Every day in the morning	

Figure 14 - List view: Medications

3.1.2 Action Plan

The action plan tool provides a simplified means of recording actions or diary entries and viewing these entries from either a table list or calendar view. Optimally, actions should be planned over a two-week period or diaries (physical activities, medication diary) might be recorded on a daily basis. Figure 15 depicts the dialog view for inserting or updating actions and Figure 16 presents the inserted actions as a table.

It is possible to enter new actions directly using the calendar view (see Figure 17), however, this feature is not activated by default because not all users are accustomed to this interacting with electronic calendars.

Basically, the information about actions in the Action Plan is not shared with other persons (such as physicians). But the patient can grant access and e.g. share the status of physical actions as feedback to clinicians via the PHRS interoperability services.

Action Details

Action Name *

Category

Have you completed this action? Done To do

When?

How long?

Comments

Briskly to the point of being slightly winded

Figure 15 – Dialog view: Actions

Options	Status	Action Name	Category	When?	How long?	Comments
	Done	Nordic Walking	Sport	2011-11-18	30 minutes	brisk walking, almost winded but felt better this time
	Done	Dr Wenger	Appointment	2011-11-30	All Day	ask about sleeping problems, low energy
	To do	Dr. Iganz	Appointment (Medical)	2011-12-03	45 minutes	

Figure 16 - List view: Actions

Sun	Mon	Tue	Wed	Thu	Fri	Sat
30	31	1	2	3	4	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30	1	2	3

Figure 17 – Calendar view: Actions

3.1.3 Health Profile

3.1.3.1 Maintaining Contact Information

This menu item allows the patient to insert and update his/her contact information. Figure 18 presents the dialog form for managing the contact data.

Contact Information

First Name: Hans

Last Name: Huber

Primary Telephone: 0664 12 34 567

E-Mail: hh@gmail.com

Organization:

Healthcare Role: Patient

Street Address: Nebenstraße 17

Postal Code: 5020

City: Salzburg

Country: Austria

Internet Chat Service: Google

Internet Voice Service: Google

Comments:

Save Cancel

Figure 18 – Dialog view: Contact Information

3.1.3.2 Indicating Risk Factors

The patient can provide basic information about their risk factors. This might be additional information for physicians. Important risk factors related to CIED patients are cholesterol, smoking, diabetes and hypertension (see Figure 19). Figure 20 and Figure 21 presents examples how to describe the profiles for smoking and for diabetes.









Risk Factor Description				
	Active	Risk Factor	Modified	Comments
 	Active	Cholesterol	2011-11-10	
 	Not answered	Smoker		
 	Not answered	Diabetes Mellitus		
 	Not answered	Hypertension		

Figure 19 - List view: Risk Factors

escription

Smoker

What do you smoke or did you smoke?	<input type="checkbox"/> Cigarette smoker <input type="checkbox"/> Cigar smoker <input type="checkbox"/> Pipe smoker
How long did you smoke?	I smoked for .. <input type="text" value="1 year"/>
Status	<input type="radio"/> Yes I currently smoke since <input type="radio"/> No, I no longer smoke as of
Date ended	<input type="text"/>
How much did you smoke?	<input type="text" value="1 pack per day"/>
Comments	<div style="border: 1px solid #ccc; height: 40px;"></div>

Figure 20 – Dialog view: Risk Factors – Smoking

Diabetes Mellitus

How do you treat this?

Diet
 Drug
 No Special treatment

If you take a diabetes medication, which do you take?

Insulin
 pills
 No Special treatment

Comments

✓ Save × Cancel

Figure 21 – Dialog view: Risk Factors - Diabetes

3.1.3.3 Activities of Daily Living

Activities of Daily Living concern the patient profile and deliver insight how a patient is able managing his/her daily routine. This menu item provides a list of activities patient can either do or requires assistance (see Figure 22). Figure 23 presents the dialog view for climbing stairs and represents one example for indicating such activities.

Activity Of Daily Living			
Options	Activity Type	Activity Status	Comments
	Bathing activity	Not answered	
	Climbing stairs	I require assistance	breathless alone
	Driving a car	I can do	need glasses
	Gardening	I can do	Hobby daily indoor and outdoor
	House work	I can do	Share takes with roommate
	Shopping activities	Not answered	

Figure 22 - List view: Activities of Daily Living

The dialog box is titled "Activity Type" and "Climbing stairs". It contains three radio buttons for "Activity Status": "I can do this without assistance" (unselected), "I require assistance" (selected), and "Not answered" (unselected). Below these is a text input field for "Comments" containing the text "breathless alone". At the bottom are "Save" and "Cancel" buttons.

Figure 23 – Dialog view: Activities of Daily Living, climbing stairs

3.1.3.4 Physical Activities

Physical activity data concerns the patient profile, although these are not actions for organizing in the action plan. These are more similar to *Activities of Daily Living* as another means to access what physical activities, such as sports or exercise, the patient can do or has done. Figure 24 presents an example for indicating jogging as a physical activity that a patient performs on a regular basis several times per week. The overview form summarizes all current physical activities of the patient (see Figure 25).

The dialog box is titled "Activity Details". It contains several fields: "Physical Activity" (dropdown menu with "Jogging" selected), "Optional activity label" (text input with "alternate walking"), "Status" (radio buttons: "I am active with this activity since" selected, "I am not currently active with this activity as of" unselected), "Date (yyyy-mm-dd)" (text input with "2010/05/11"), "How often do you do this activity?" (dropdown menu with "Several times per week" selected), "How long do your perform this activity?" (dropdown menu with "45 minutes" selected), and "Comments" (text input with "slow jog"). At the bottom are "Save" and "Cancel" buttons.

Figure 24 – Dialog view: Physical Activities

Physical Activity

+ create

Navigation: << 1 >>

Options	Category	Status	When?	How long?	Comments
	Jogging	I am active with this activity since	2010-05-11	45 minutes	slow jog
	Bicycle riding	I am active with this activity since	2010-05-12	1 hour	slow pace to work

Navigation: << 1 >>

Figure 25 - List view: Physical Activities

3.1.4 Monitoring Vital Signs

The monitoring section provides an overview of current health information and charts of historical information. Additional information and charts can be added as needed. The following are examples for date (body weight and blood pressure) that the patient might wish to follow and perhaps share with their physician:

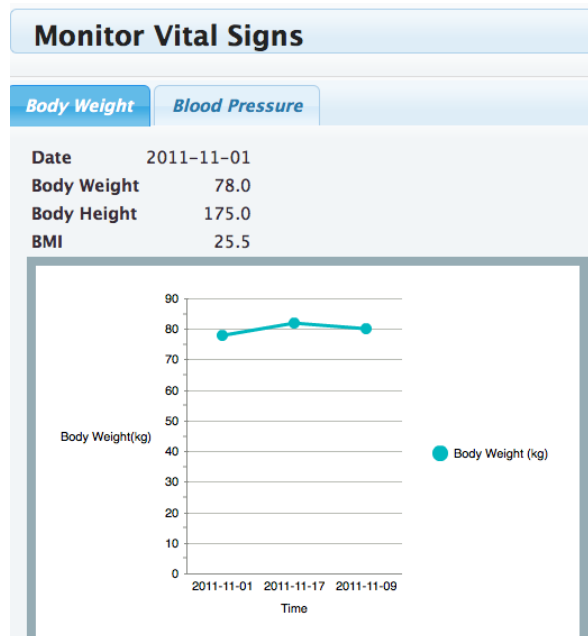


Figure 26 – Monitoring Body Weight

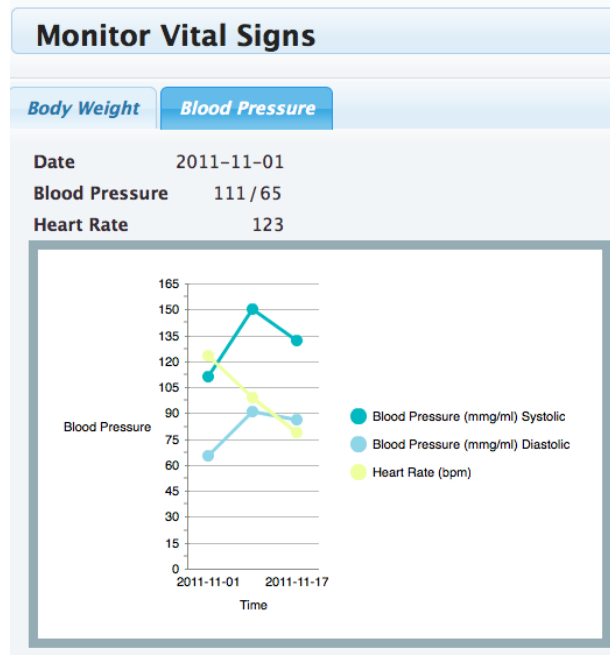


Figure 27 – Monitoring Blood pressure

3.2 Information and People

This menu item is dedicated to health information customized for CIED patients and comprises the following topics:

- Health Topics – includes information and education material and decision aids for CIED patients
- Community – allows patients to share information and experiences with other patients in similar situations by using social software tools
- Contacts – allows patients to insert contact data about medical persons such as the treating cardiologist or other persons.


3.2.1 Health Topics

The PEF provides light integration to a Content Management portal (CMS) where patient education materials can be created and managed for CIED patients. A detailed description about information and education material can be found in D521 “Patient Education Mechanisms for the PHR”. The main topics are listed in Figure 28:

▼ Information & People
▼ Health Topics
<u>Basic Information</u>
New Habits
Precautions
Warning Signs
Decision Aids
Links
Glossary

Figure 28 – Menu Overview: Patient Information

An example for the sub menu items *New Habits* is presented in Figure 29.



New Habits

1 Added by [mule](#), last edited by [Manuela](#) on 2011-10-13 ([view change](#))

- Introduction
- Changing your habits
- Work, profession and housework
- Free time, travelling and transport
- Questions and answers:
 - How do I live with my ICD?
- How do I live with my pacemaker?
- Getting started with your pacemaker: The first six weeks
- What I can do with my pacemaker?
- You and I are very well blended
 - Appliances
 - Mobile
 - Sports
 - Travel
 - Airports
 - Department stores
 - Hospitals
 - Family
 - Effect of magnets
- What things I can make carrying an ICD or a pacemaker?
- References:

Introduction

After you have left the hospital, you should allow some months to get used to the situation. Speak with your family and friends about the ICD.

Although this will not heal the underlying disease in your heart, it can make you feel more secure. Initial doubts and fears can often be allayed by conversations prevent the effect of possible tachycardia and the patients therefore benefit from a real improvement in their quality of life.

Changing your habits

You must pay attention to certain things immediately after the operation.

You should observe the scar and inform your doctor if it becomes red, swells or becomes moist. You should not move the affected shoulder too energetic is also inadvisable at the beginning.

After discussing the situation with your doctor, there is no problem with taking walks, playing sports or bathing. The clothing round the wound should not t

Once the wound has completely healed, there is nothing to stop you from taking up new pursuits. As long as your doctor has no objections, you can resu

With the implanted ICD, most patients can increase the scope of their activities - as the ICD removes the fear of being helpless during an attack of arrhyt


Work, profession and housework

You can also start being active again at your place of work and in the house. However, you should avoid some activities, such as climbing ladders, weldin

Theft protection systems, as found in the entrances and exits of department stores, do not normally present a risk for someone with a defibrillator. Howev

Figure 29 - Patient Education Example: New Habits

In the following Figure 30 is an example for a *Decision aid for telemonitoring Y/N*. Commonly, decision aids describe different aspects of a decision situation such as advantages and disadvantages, risks and possible alternatives.



Decision Aid for Telemonitoring

✎ 1 Added by [mule](#), last edited by [Manuela](#) on 2011-10-13 ([view change](#))

Decision aid for telemonitoring Y/N

The aim of this decision aid is to help patients with a Cardiovascular Implantable Electronic Device (CIED) to decide whether or not bel

Definitions

CIED, Cardiovascular implantable electronic device (CIED) (from the HRS_ERA Expert Consensus of CIEDs¹): Cardiovascular implant pacemaker (PM), implantable cardioverter-defibrillator (ICD), cardiac resynchronization device (CRT), implantable loop recorder (ILR) ; (ICM). PM, ICD and CRT devices have been described in detail in the google site and will be implemented in the PHR and all of these cardiovascular implantable electronic devices (CIEDs).

Alerts: Some CIED have alert capabilities.

Home monitor/communicator (from the HRS_ERA Expert Consensus of CIEDs¹): A device designed to receive telemetry from a specific using telephone technology to a remote-secure monitoring center or file server. Often the home monitor/communicator is stationary and analog telephone line in a patient's home, but it can also be mobile/portable unit and connected via cellular technology.

In-Clinic Follow-up

Patients with a CIED must be followed-up in an out-patient clinic (include follow up guidelines), where the physicians can assess the de CIED collects a large amount of information such as technical device parameters and clinical relevant data. All this information may hel

- Assess whether the device is working properly
- Detect present or anticipate future device dysfunction
- Keep track of the disease progress
- Help taking medical actions

Goals of monitoring CIEDs (HRS-ERA Expert Consensus of CIEDs):

Goals	
Patients related	<ul style="list-style-type: none"> • Optimize the patient's quality of life. • Optimized pacemaker/ICD system function to meet the patient's clinical requirements. • Identify patients at risk and initiate appropriate follow-up with field safety corrective action and saf • Triage non CIED related health problems and make appropriate referrals.
CIED related	<ul style="list-style-type: none"> • Document appropriate CIED function. • Identify and correct abnormal CIED behavior. • Maximize pulse generator longevity while maintaining patient safety. • Identify CIEDs approaching end of battery life, to identify leads at risk of failure, and to organize CIE manner.
Disease related	

Figure 30 – Patient Education Example: Decision Aids

3.2.2 Community related topics

The community related topics include a list of community links, forums for patients and healthcare providers, blogs, and information discovery via community bookmarks and by browsing content by keyword.

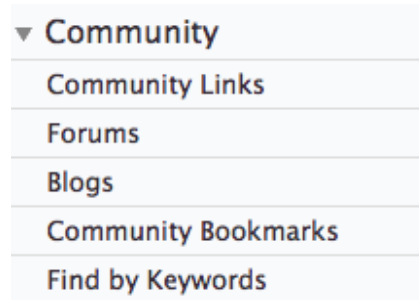


Figure 31 - Menu view: Community

3.2.3 Contacts

Contact information of a patient's healthcare providers can be viewed and managed. The telephone or email might be sufficient to facilitate feedback to patients, however, chat and VoIP (Voice over IP) will depend on how the healthcare professional wishes to communicate.

The screenshot shows a 'Contact Information' dialog box with the following fields and values:

- First Name: Manuela
- Last Name: Mayer
- Primary Telephone: 0680 12 34 567
- E-Mail: mm@gmail.com
- Organization: (empty)
- Healthcare Role: Other (dropdown)
- Street Address: 123 Hauptstraße
- Postal Code: 5020
- City: Salzburg
- Country: Austria
- Internet Chat Service: Skype (dropdown)
- Internet Voice Service: Skype (dropdown)
- Comments: Cardiologist, consultation hours: Monday - Friday 8:00 - 12:00

At the bottom of the dialog are 'Save' and 'Cancel' buttons.

Figure 32 – Dialog view: Contacts

3.3 Privacy – Patient Consent Editor

Privacy settings primarily affect the sharing of information with clinical systems via the PHRS interoperability services. A patient can manage privacy settings using the patient Consent Editor that is based on roles (e.g. physicians, nurses or family member) and can be granted for different categories of patient data such as medication. A detailed description of the Consent Editor can be found in D5.4.1 Patient Consent Management and Security).

3.4 Sharing of personal health information and interoperability

The patient consent editor and PHRS interoperability services regulate the sharing of personal health information with clinical systems. The PHRS creates a unique PHRS user health profile identifier that can be mapped to patient identifiers shared by clinical systems seeking access to PHRS patient data. When the patient saves or updates their PHR information, this information is persisted and then enriched and forwarded to the PHRS interoperability service repository.

The transformed data must conform to the standard coding understood by the interoperability services. The interoperability services use the IHE CM Profile and utilize standardized vocabularies, such as UMLS, LOINC, and SNOMED. The interoperability client software includes a SKOs¹⁴ based RDFS¹⁵ ontology (Simple Knowledge Organization) contains relevant standard vocabularies, simple labels, and organized with relevant query tags for use by User Interfaces. The PHR portal sends messages containing new or updated patient health information to the PHRS interoperability component and these messages are persisted separately by that component.

The PEF framework includes tools to filter, enrich and transform PHRS patient data. Content enrichment steps include transforming any local codes to standard medical codes and filtering data that should not be shared, such as private notes or comments. The interoperability client is used to exchange information with the PHRS interoperability component.

4 PEF Tool Technologies

One PEF framework goal is to provide an infrastructure using open source software that facilitates the adaption, reuse and contribution software by developers.

As described in the previous section (Principals followed), a task was to explore and develop prototypes using various web frameworks that might facilitate both the future uptake of the PEF as an open source project, and future development of new domain models, views and functionalities.

The current PEF prototype provides software tools facilitate development for specific web frameworks involving Groovy, Java, and JSF 2.0 libraries (Apache MyFaces and PrimeFaces). PEF tools handle common JSF tasks or problems that will facilitate future development.

- User interface templates and code fragments, component utilities libraries
- User interface scaffolding and template tools,

¹⁴ SKOS Single Knowledge Organization <http://www.w3.org/2009/08/skos-reference/skos.html>

¹⁵ RDFS <http://www.w3.org/TR/rdf-schema/>

- Base controllers or managed beans that can be extended to manage new domain models.
- JSF utilities that handle common problems during the JSF lifecycle

The portal functionalities (section PEF PHR Portal Functionalities) demonstrate the use of the framework to implement new MVC based software; the views, controllers and domain models extend base PEF models, controllers and views templates, UI components or view fragments. User Interfaces are decorated by using JSF composition and JSF templates.

The use of the PrimeFaces library provides rich JSF UI components that effectively hide most JavaScript and AJAX programming, except for the common boilerplate validation scripts. Additional template support has also included Groovy scripts to help generate scaffolds for new User Interfaces and their software controllers. These will be refactored later to the next version of PrimeFaces (3.0) Scaffolds help developers build rapidly and modify what they need.

4.1 PEF Domain models extend common high level schema

A common high level data model schema is used when creating new domain models. Domain models for a new web form should extend the commons property schema. The common model facilitates access, access control, PHRS interoperability with regard to IHE profiles and semantic interoperability across PEF models. Additional temporal properties are needed for most, but not all domain models supporting health information data models.

Continued development of domain models might continue to effect changes to the common data model, and fortunately, the persistence technology (NoSQL document-oriented) supports flexible models and modelling. Coupled with a map reduce engine, the PEF can support alternate data views created by map reduce functions, and possibly alternative User Interfaces based on those data views.

4.2 MVC web framework and PEF Web Development

The choice of an appropriate base web framework technology is an extremely difficult one. The first decision was to explore and develop prototypes using various web frameworks that would facilitate both the future uptake of the PEF as an open source project, and future development of new domain models, views and functionalities. The negative experiences using JSF 1+, led to an early decision to avoid JSF all together. JSF 2.0 is argued to support a richer Model View Controller (MVC) concept, closer to a traditional GUI application¹⁶.

¹⁶ JSF MVC <http://www.ibm.com/developerworks/library/j-jsf1/>

The Model-View-Controller (MVC) based web infrastructure is supported by:

- Reusable and extendable common model,
- Extendable software controllers for handling common User interface interaction patterns
- JSF/PrimeFaces based view templates, and UI code fragment, provide AJAX and non-AJAX functionalities. AJAX is built-in supporting the JSF 2.0 AJAX API.
- Supporting tools for health calculations and charts
- JSF utilities that handle common issues with JSF lifecycle and other issues

PEF common software controllers and JSF managed beans handle core PEF functionalities for web form and other UI interactions. These controllers should be extended to support current and new domain models and views. The event-based model is standards based using tools based on Java beans specification¹⁷ and JSF 2.0 (and JSF 2.0 AJAX) specification¹⁸

To support Java Server Faces (JSF), additional utilities were created and integrated into the base software UI controllers. These functionalities are a reusable means to address common issues or problems encountered with JSF form and validation handling.

Supporting future user interface development

- Base PEF controllers support particular UI patterns and are extendable. The primary pattern involves the data management, query list interactions, UI integration of controlled vocabularies into UI widget (UI selection lists, etc.) with added internationalization support.
- UI building support
 - Reusable views for combining into new Views. For example, dialogs, charts, and other managed lists might be recombined.
 - UI Code fragments and snippets,
 - Groovy based scaffolding templates support the creation of UIs that can be further modified
 - Map Reduce engine facilitates the creation of new views based on available data sources. This is important to the open source strategy considering the expected growth of additional views and models. Aggregating and recombining data into new views would be an advantage.

Supporting Health related functions and visualization

PEF supports a common health API for supporting visualization of health data (charts and calendars/ schedules), basic calculations (e.g. BMI) and validation rules.

The PEF health visualization API supports only UI components based on the PrimeFaces library. The data spreadsheet feature will become available pending the next release of the JSF libraries. Spreadsheets might help patients work better with specific types of data gathering activities.

¹⁷ Java Beans Specification <http://www.oracle.com/technetwork/java/javase/documentation/spec-136004.html>

¹⁸ JSF 2.0 Specification

4.3 Technology Overview

Table 2 provides an overview of external open source software libraries used by PEF. Some software is either optional. Over time while refactoring PEF, some libraries might be replaced, removed or substituted.

Role	Software	Version	License
CMS, social software, patient materials, feedback forums	Atlassian Confluence ¹⁹		Atlassian Open Source License issued to SRFG as open source project
OpenID	Atlassian Crowd/CrowdID ²⁰ supporting OpenID		Atlassian Open Source License
Optional: CMS, social software, patient materials, feedback forums	Liferay ²¹ Portal 6.1 Community Edition		
UI	Apache MyFaces ²² (Java Server Faces 2.0) The issue of JSF 2.0 brought renewed interest to JSF after negative experiences with JSF 1.0. Oracle's reference implementation, Mojarra, is also available.	2.0.x	Apache License 2.0
UI	PrimeFaces ²³ is an open source component library for JSF 2.0. Lightweight, but it provides rich set of UI components, built-in AJAX on standard JSF 2.0 Ajax APIs, Widget toolkits and UI tags hide components based on JavaScript or HTML 5. Supports Mobile UIs for future PEF applications Good documentation and code examples. Growing and supportive developer community. PrimeFaces supports portlet ²⁴ environments based on JSF 2 and Portlet 2.0 APIs. A portlet bridge is necessary to run a JSF application as a portlet.	2.2.1	Apache License 2.0
Common	Primary programming language: Groovy ⁵ combined with Java and Java based libraries	1.8.x	Apache License 2.0

¹⁹ Atlassian Confluence Wiki

²⁰ Atlassian CrowdID <http://confluence.atlassian.com/display/CROWD/CrowdID+Administration+Guide>

²¹ Liferay Portal <http://www.liferay.com/>

²² Apache MyFaces <http://myfaces.apache.org/>

²³ PrimeFaces <http://www.primefaces.org/>

²⁴ PrimeFaces portlet bridge <http://primefaces.googlecode.com/svn/examples/trunk/prime-portlet>

Common	Java programming language	1.6	GPL, Java Community Process
UI	Optional as demonstration: ZK CE web application framework	5.0.9	LGPL (community edition)
Authorization, Security	Spring Security ²⁵ , OpenID support	3.0.7	Apache License 2.0s
Authorization	Openid4java ²⁶ OpenID 2.0, RP RelyingParty	0.96	Apache License 2.0
Authorization	Dyuproject ²⁷ OpenID 2.0, RP RelyingParty	1.1.7	Apache License 2.0
Vocabulary, Interoperability	Sesame triplestore	2.5x	Sesame BSD style license
Persistence	MongoDB ²⁸ is a scalable, open source, document-oriented database (NoSQL)	1.8.3	AGPL v3.0.
Persistence	MongoDB Driver is used by Morphia	2.3	Apache License 2.0
Persistence	Morphia ²⁹ is a lightweight type-safe library for mapping Java objects to/from MongoDB Supports the PEF data access tools.	0.99	Apache License 2.0

Table 2 - Overview of Software Libraries

4.4 Persistence Technology

MongoDB²⁸ is a document-oriented NoSQL technology. The three primary reasons for choosing the NoSQL document centric persistence approach are:

- Supports flexible data models
- Supports Big Data⁶
- Supports Map Reduce functionalities with a map reduce³⁰ engine. Data aggregation/recombination, terminology mapping to support alternative data views.

The many Microsoft HealthVault³¹ XML schemas and data models from other PHR systems were examined during the State of the Art analysis. Given the diversity and difficulty of managing and semantically integrating these data models, the PEF persistence technology choice will address our concerns regarding flexible data models and modeling, and big data issues. The combination of a document-oriented store and Map Reduce engine can be useful for handling heterogeneous and potentially overlapping data models for information gathering. Map Reduce is an additional means to aggregate and compile information and found in PHR systems. In the future, one might expect similar and even

²⁵ Spring Security www.springsource.org/spring-security

²⁶ <http://code.google.com/p/openid4java/>

²⁷ <http://code.google.com/p/dyuproject/>

²⁸ MongoDB <http://www.mongodb.org>

²⁹ Morphia <http://code.google.com/p/morphia/>

³⁰ <http://www.mapreduce.org/>, <http://en.wikipedia.org/wiki/MapReduce>,

³¹ Microsoft HealthVault <http://www.microsoft.com/en-us/healthvault/>

overlapping domain models for gathering patient information – there are no standardized data collection forms. The tools should be flexible to handle this diversity. One important attraction of CouchDB has been the ability and capability of easily creating new data views - this is desirable for health information, especially considering the diversity of healthcare applications today and the diversity of models for collecting information. The PEF flexibility in this regard might become important to the future open source strategy.

Lastly, auditing and versioning of data is facilitated by this persistence store technology choice because it is possible to write the data to more than one data catalogue quite easily. The technology facilitates the attachment of software listeners (observers) that handle and trigger audit events. The PEF persistence client provides auditing and versioning over the MongoDB document repository

4.5 User Authorization and Security

The PEF framework produced intermediate prototypes utilizing Apache Shiro³² and Spring Security²⁵ frameworks. The shift to OpenID as the primary iCARDEA authentication approach is an important innovation for enabling healthcare and patient digital identities seamlessly across healthcare applications.

4.5.1 About OpenID

OpenID is an open standard that allows users to authenticate to websites without having to create a new password. Figure 33 describes the process of user authentication using OpenID. The OpenID provider can be one of many known providers that can authenticate a user for a participating application. In the case of the PHR System, the iCARDEA OpenID provider can be configured as the sole OpenID provider.

OpenID is an open standard that describes how users can be authenticated in a decentralized way, providing users with reusable digital identities OpenID³³. The most relevant aspect is that OpenID facilitates the integration of healthcare applications by enabling one common user identity. Applications might still require a separate user account and then allow the user to associate an OpenID with their local application user account. Particular for applications on the same web domain, users do not need to login each time via OpenID, the browser and application remember the user. The latter issue is a key strategy for the PEF integration with other healthcare applications or with content management and forum portals.

³² Apache Shiro <http://shiro.apache.org/>

³³ OpenID <http://openid.net/>

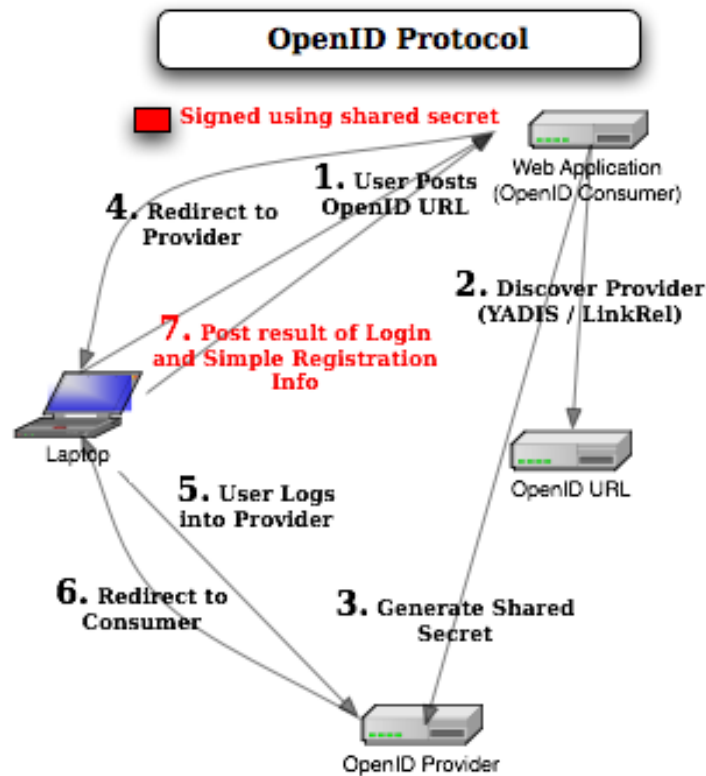


Figure 33 – User Authentication: OpenID Protocol Diagram³⁴

4.5.2 A common digital identity for a patient or healthcare professional across healthcare applications

The iCARDEA system supports iCARDEA components with an OpenID provider service. This creates a shared digital user identity across all components and facilitates common integration of iCARDEA components. For example, a common OpenID provider supports all iCARDEA components including the Patient Consent Editor (Task 5.4 Security and Privacy, D5.4.1) and the PHR portal. With one common user identity across all components, there is no need to resolve whether one local application user is the same user in another application.

In the early prototypes there was support of security frameworks Apache Shiro and later Spring Security. User authentication is straight forward normally in terms of user interaction, however, adding OpenID allows at least two scenarios:

- A user creates a local user account with a user name and password. Later the user might add OpenIDs to these accounts. From a login page, the user might login using either his/her local user name or their OpenID approach.
- Authenticating via an OpenID triggers the creation of a new user account either silently or with minimal user interaction – for example, to ask for data not extracted from the OpenID attributes.

³⁴ <http://leancode.com/2007/02/23/openid-protocol-diagram/>

The main challenge to using existing security frameworks is whether OpenID is already an authentication option. Apache Shiro has no release supporting OpenID, only some unreleased code. Spring Security's OpenID plugin does not expose and support the use of Simple Registration³⁵, a lightweight profile exchange. As a result, the three OpenID packages (Spring OpenID, Openid4java, and Dynuproject) were investigated and from these basic OpenID implementations were assembled. A particular implementation might be suitable and that can be configured in the web application.

In conclusion, iCARDEA has innovated the use of OpenID for creating a common digital identify for patients or healthcare professionals that enable users to maintain their unique digital identity over a variety of applications supporting healthcare. For the patient and healthcare provider, it means that they can utilize healthcare applications using one OpenID identifier (username) and password. In many cases, they might not need to login again to access another application.

4.5.3 Configure the User Authentication approach

For testing in the pilot application, a test user can use pre-established accounts local to the PHR system, authenticate via the iCARDEA OpenID Provider. (Optionally, an OpenID test provider can be setup for component testing).

Currently, the PEF does not allow the user to add OpenID to an existing user account, however, that will be considered. In earlier prototypes, two user authentication and security frameworks were used: Spring security and Apache Shiro. Base on these frameworks, local users could be created. The shift to OpenID, however, required a new approach – whether to require the creation of a local account and then associate one or more OpenIDs to that account. Spring Security's OpenID plugin, was the natural choice, however, it was discovered that it does not support OpenID Simple Registration. Consequently, the PEF provides OpenID implementations using three different libraries.

4.6 Privacy

4.6.1 Consent Manager

Task 5.4, provides a Consent Manager component that enables patients to control access to their health information by external systems e.g. clinical and other PHR systems. The PHR portal menu can provide access to any iCARDEA web application that is support by the common iCARDEA OpenID provider service. Based on the shared patients' OpenID digital identities, the Patient Consent Editor can be integrated with PHRS portal as well as other iCARDEA components.

³⁵ OpenID Simple Registration Extension http://openid.net/specs/openid-simple-registration-extension-1_0.html

4.6.2 Securing stateful information in Web applications

Stateful information can pose a security risk, especially if stored by a web technology on the client browser. With a JSF based infrastructure, stateful information can be stored either in the client or in the server session. Fortunately, the server can be configured to keep the stateful data in the session or to encrypt the data and store it in the client.

4.7 Patient Feedback and Patient Education

Atlassian Confluence and Liferay portals were the focus of integration in the PEF development. Besides popularity of these portals, the choices were also a means to improve the uptake and exploitation of the PEF framework by providing examples. The current PEF prototype uses Atlassian Confluence and plugins to support content management and social functionalities such as content authoring, forums, tagging, and bookmarking. Specific plugins from these popular portal frameworks can be added as needed to support patient needs.

Both portal products have some degree of OpenID support. As OpenID becomes more popular, the product support and capabilities for OpenID are expected to improve, although both products require users to first create a local user account. Atlassian provides CrowdID to support administrators to add OpenIDs to user accounts.

To summarize what has been learned, the main questions for integrating any future portal product are:

- Is it possible to integrate an application because of its underlying web technology? (Technologies such as JSF, Struts, Grails, PHP, etc.)
- Is there portal plugin architecture or portlet bridge software for integrating an application based on a particular web technology? Are there other means?
- How can the application integrate portal user management and authentication system? Is there OpenID support?

4.8 Vocabulary and Internationalization Tools

Internationalization is supported by both Java internationalization and by a **SKOError! Bookmark not defined.**s based controlled vocabulary support interoperability requirements.

Additional vocabulary tools support both User interfaces and interoperability requirements. The vocabulary tools help also to extend the controlled vocabulary provided by the PHRS interoperability services. The SKOs based vocabulary provided by the PHRS interoperability component cannot provide all possible variations of labels needed in a user interface. For example a standard code for a status is labelled “completed”, a simple label.

However, domain specific meanings for this status code are required in particular UIs. The PEF software provides different strategies for extending labels:

- Provide code and labels resource bundles for each UI
- Tools to lookup specific labels in different sources e.g. first search internationalization resource bundles, then search for the default label in the controlled vocabulary

Lastly, as a summarization:

- Controlled vocabularies support interoperability services and UI form handling and information viewing
- Java resource bundles provide UI internationalization provide UI labelling and also extend the controlled vocabulary internationalization where needed by the User interfaces.
- Vocabulary enhancement tools enhance the vocabularies for use in the User Interfaces (selection lists, radio boxes)

4.9 Interoperability Tools

The PEF framework has an interoperability client API that facilitates the exchange of messages for each domain object. When a user changes their health data, messages can be sent through the interoperability client and ultimately made available for sharing with clinical or other PHR systems (Task 6.3 PHR Interoperability). The interoperability client API (Data access object pattern³⁶) abstracts the low level interoperability API into a high-level domain specific language. If a new domain model is implemented for the PEF, the developer might either reuse existing high-level API or extend this API for the new domain model.

Interoperability services require specific vocabulary in messages it receives from the PHR portal. PEF terminology tools support the mapping of local codes to the controlled vocabulary required by the interoperability service. These are based on Enterprise Integration message transformation patterns³⁷) However, it is emphasized to use the controlled vocabulary in the PEF framework, however, sometimes it is necessary to use local codes and map those codes appropriately to the standard ones.

5 Outlook

The software will be released as an open source project. Any feedback from the WP 9 iCARDEA pilot application will be added to a features or issues list. The current software and library dependencies will be updated as needed to address bugs, feature changes or new features.

³⁶ Data Access Object Pattern <http://java.sun.com/blueprints/corej2eepatterns/Patterns/DataAccessObject.html>

³⁷ Message Transformation Patterns <http://eaipatterns.com/MessageTransformationIntro.html>